

Testimony of Carolina Hinestrosa

We'll now hear from Ms. Hinestrosa.

MS. HINESTROSA: Good morning. My name is Carolina Hinestrosa. I am a 10-year, two-time breast cancer survivor. I'm a mother of a 13-year-old daughter. I'm also the executive vice president for programs and planning of the National Breast Cancer Coalition.

My first diagnosis with breast cancer was at the age of 35. My second diagnosis was at the age of 40. My younger sister was also diagnosed twice, first at age 29, and then at 34. Over Christmas last year, two of my cousins and an aunt were diagnosed with breast cancer as well. Of course, we suspect there is a genetic mutation that predisposes members of my family to breast cancer.

I sought genetic counseling as part of a study. After carefully weighing the potential benefits and harms of genetic testing, I decided not to undergo testing for fear of potential consequences to my daughter. My fears are two-fold, first that the information may not be protected and might even be misused. I also worry that if I test positive, my daughter might be obligated to disclose the presence of a genetic mutation and that she might suffer future discrimination in health insurance and employment as a consequence.

I have four sisters and a brother. We all worry about our risk for breast cancer and the potential risk for our daughters, yet none of us feel safe enough to undergo genetic testing. My family experience illustrates why our nation needs strong nondiscrimination laws.

Since its founding in 1991, the National Breast Cancer Coalition, of which I am a member and am executive vice president, has changed the world of breast cancer in public policy, science, industry and advocacy by empowering those with breast cancer, our families and friends, and creating new partnerships, collaborations, research foundation opportunities, and avenues for quality access to health care.

The National Breast Cancer Coalition is now over 600 strong in terms of organizations who are members, and we represent several million patients, professionals, women, our families and friends. Coalition members include cancer support information and service groups, as well as women's health and provider organizations.

The mapping of the human genome has brought with it the promise of reducing human suffering by targeting interventions for those at risk for disease. The National Breast Cancer Coalition believes that strong legislative and regulatory strategies must be established to address the protection of individuals from the misuse of genetic information at the national, state and local levels of government. Genetic information is uniquely private information that should not be disclosed without authorization by the individual. Improper disclosure can lead to significant harm, including discrimination in the areas of employment, education, health care, and insurance.

The 1996 Health Insurance Portability and Accountability Act, HIPAA, took significant steps toward extending protection to individuals from genetic discrimination in the health insurance arena by creating privacy standards, but this law does not go far enough. It is time to extend protections against genetic discrimination to everyone. The development of new genetic tests necessitates legislative and regulatory strategies to address the issue of how to protect individuals from the misuse of their genetic information.

Fear of potential discrimination threatens both a woman's decision to use new genetic

technologies and to seek the best medical care. Women are also afraid to enroll in research and clinical trials that involve genetic studies, and this in turn threatens the viability of the scientific community to conduct the research necessary to understand the cause and find a cure for breast cancer. Many of the women testifying at present in this audience today have experienced exactly those concerns.

NBCC strongly supports the enactment of legislation that would protect millions of individuals against discrimination not only in health insurance but also in the workplace and that will provide strong enforcement mechanisms that include the private right of action. For this reason, NBCC supports H.R. 1910, the Genetic Nondiscrimination Health Insurance and Employment Act authored by Congresswomen Louise Slaughter. This legislation prohibits health plans from requesting, requiring, collecting or disclosing genetic information without prior specific written authorization of the individual; from using genetic information or an individual's request for genetic services to deny or limit any coverage, to establish eligibility, continuation, enrollment, or contribution requirements; and from establishing differential rates or premium payments based on genetic information or an individual's request for genetic services.

This legislation also prohibits employers from using genetic information to affect the hiring of an individual or to affect the terms, conditions, privileges, benefits, or termination of employment unless the employment organization can prove this information is job related and consistent with business necessity. Also, from requesting, requiring, collecting or disclosing genetic information prior to a conditional offer of employment; or under all other circumstances requesting or requiring collection or disclosure of genetic information unless the employment organization can prove this information is job related and consistent with business necessity.

It also prohibits from accessing genetic information contained in medical records released by individuals as a condition of employment in claims filed for reimbursement for health care costs and other services. Also, it prohibits releasing genetic information without specific prior written authorization of the individual.

Most importantly, H.R. 1910 contains strong enforcement language and provides individuals with a private right of action to go to court for legal and equitable relief if they are a victim of genetic discrimination whether they are subject to discrimination by the health plan or the employer.

NBCC does not support the Genetic Nondiscrimination in Health Insurance and Employment Act, S. 1053, passed by the Senate in October 2003, because it does not contain sufficient enforcement provisions. Unlike H.R. 1910, S. 1053 does not provide individuals with a private right of action should they become a victim of genetic discrimination in the individual insurance market. NBCC believes that a right with no enforcement is really not a right at all. It is for that reason that no matter how carefully a bill is worded, no matter how much effort is put into it, including protections that breast cancer patients need, if that bill does not have a strong enforcement mechanism, then NBCC will not support it.

As we clearly can see from the witnesses here today, genetic discrimination is a real and growing problem that needs an immediate solution, not one that should wait until we have further cases of women and men who have experienced this type of discrimination that is so detrimental to the ability to seek quality health care.

Thank you for the opportunity to share the views of the National Breast Cancer Coalition.

MS. MASNY: Thank you very much for your own personal experience, as well as for the views

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of the National Breast Cancer Coalition.